

# Terms and conditions for the use of data downloaded from the CSVS database

*Last updated: October 28, 2020*

This agreement governs the terms on which access will be granted to the data of the Collaborative Spanish Variant Server ([CSVS](#)).

In signing this agreement, You are agreeing to be bound by the terms and conditions of access set out in this agreement.

For the sake of clarity, the terms of access set out in this agreement apply both to the User and the User's Institution (as defined below). User Institution and User are referred to within the agreement as "You" and "Your" shall be construed accordingly.

## **Definitions:**

CSVS data make reference to the aggregated genomic data coming from different genomic projects that include the Medical Genome Project (MGP)<sup>1</sup>, CIBERER<sup>2</sup>, the Navarra Genomics Project (NaGen)<sup>3</sup> and others, binned according top level ICD10 categories<sup>4</sup>.

Data Subject means a person, who has been informed of the purpose for which the Data is held and has given his/her informed consent thereto.

User means a researcher whose User Institution has previously completed this Data Access Agreement and has received acknowledgement of its acceptance.

Publications means, without limitation, articles published in print journals, electronic journals, reviews, books, posters and other written and verbal presentations of research.

User Institution means the organization at which the User is employed, affiliated or enrolled.

## **Terms and Conditions:**

In signing this Agreement:

1. You agree to use the Data only for the advancement of medical and scientific research, according to the consent obtained from sample donors.
2. You agree not to use the Data or any part thereof for the creation of products for sale or for any commercial purpose.

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<sup>1</sup><http://www.medicalgenomeproject.com/en>

<sup>2</sup><https://www.ciberer.es/en>

<sup>3</sup><https://www.nagen1000navarra.es/en>

<sup>4</sup><http://apps.who.int/classifications/icd10/browse/2016/en#>

3. You agree to preserve, at all times, the confidentiality of information and Data pertaining to Data Subjects. In particular, you undertake not to use, or attempt to use the Data to compromise or otherwise infringe the confidentiality of information on Data Subjects and their right to privacy, including attempts of subject re-identification.

4. You agree not to attempt to link the data provided under this agreement to other information or archive data available for the data sets provided, even if access to that data has been formally granted to you, or it is freely available without restriction, without specific permission being sought from the relevant access committees.

5. You agree not to transfer or disclose the Data, in whole or part, or any identifiable material derived from the Data, to others, except as necessary for data/safety monitoring or programme management. Should You wish to share the Data with a collaborator outwith the same Institution, the third party must make a separate application for access to the Data.

6. You agree to use the data for the approved purpose and project described in your application; use of the data for a new purpose or project will require a new application and approval.

7. You accept that Data will be reissued from time to time, with suitable versioning. If the reissue is at the request of sample donors and/or other ethical scrutiny, You will destroy earlier versions of the Data.

8. You agree to abide by the terms outlined in the CSVS Publications Policy as set out in Schedule 1.

9. You agree to acknowledge in any work based in whole or part on the Data, the published paper from which the Data derives, the version of the data, and the role of the CSVS and the relevant primary collectors and their funders. Suitable wording is provided in the Publications Policy given in Schedule 1.

10. You accept that the CSVS, the original data creators, depositors or copyright holders, or the funders of the Data or any part of the Data supplied: a) bear no legal responsibility for the accuracy or comprehensiveness of the Data; and b) accept no liability for indirect, consequential, or incidental, damages or losses arising from use of the Data, or from the unavailability of, or break in access to, the Data for whatever reason.

11. You understand and acknowledge that the Data is protected by copyright and other intellectual property rights, and that duplication, except as reasonably required to carry out Your research with the Data, or sale of all or part of the Data on any media is not permitted.

12. You recognize that nothing in this agreement shall operate to transfer to the User Institution any intellectual property rights relating to the Data. The User Institution has the right to develop intellectual property based on comparisons with their own data.

13. You accept that this agreement will terminate immediately upon any breach of this agreement by You and You will be required to destroy any Data held.

14. You accept that it may be necessary for the CSVS or its appointed agent to alter the terms of this agreement from time to time in order to address new concerns. In this event, the Consortium or its appointed agent will contact You to inform You of any changes and You agree that Your continued use of the Data shall be dependent on the parties entering into a new version of the Agreement.

15. You accept that the Data is protected by and subject to international laws, including but not limited to the Spanish Data Protection laws "*Ley Orgánica 3/2018, de 5 de diciembre, de Protección de Datos Personales y garantía de los derechos digitales*"<sup>5</sup>, and that You are responsible for ensuring compliance with any such applicable law. The MGP Data Access Committee reserves the right to request and inspect data security and management documentation to ensure the adequacy of data protection measures in countries that have no national laws comparable to that which pertain in the EEA.

16. This agreement shall be construed, interpreted and governed by the laws of Spain and shall be subject to the non-exclusive jurisdiction of the Spanish courts.

## **SCHEDULE 1**

### Publications Policy

The CSVS is born with the purpose of supporting health research so it will be possible to know and to characterize a large number of genetically-based diseases, essentially, rare diseases.

The CSVS anticipates that data generated from different projects will be used by others, such as required for developing new analytical methods, in understanding patterns of variation and in guiding selection of markers to map genes involved in specific diseases.

Authors who use data from the project must acknowledge the CSVS citing the relevant primary publication:

Peña-Chilet M, Roldán G, Perez-Florido J, Ortuño FM, Carmona R, Aquino V, Lopez-Lopez D, Loucera C, Fernandez-Rueda JL, Gallego A, García-García F, González-Neira A, Pita G, Núñez-Torres R, Santoyo-López J, Ayuso C, Minguez

[5<https://www.boe.es/eli/es/lo/2018/12/05/3>](https://www.boe.es/eli/es/lo/2018/12/05/3)

P, Avila-Fernandez A, Corton M, Moreno-Pelayo MÁ, Morin M, Gallego-Martinez A, Lopez-Escamez JA, Borrego S, Antiñolo G, Amigo J, Salgado-Garrido J, Pasalodos-Sanchez S, Morte B; Spanish Exome Crowdsourcing Consortium, Carracedo Á, Alonso Á, Dopazo J. CSVS, a crowdsourcing database of the Spanish population genetic variability. *Nucleic Acids Res.* 2020. doi: [10.1093/nar/gkaa794](https://doi.org/10.1093/nar/gkaa794). Online ahead of print

If you use the MGP dataset you must acknowledge the MGP project citing the publication:

Dopazo J, Amadoz A, Bleda M, Garcia-Alonso L, Alemán A, García-García F, Rodriguez JA, Daub JT, Muntané G, Rueda A, Vela-Boza A, López-Domingo FJ, Florido JP, Arce P, Ruiz-Ferrer M, Méndez-Vidal C, Arnold TE, Spleiss O, Alvarez-Tejado M, Navarro A, Bhattacharya SS, Borrego S, Santoyo-López J, Antiñolo G. 267 Spanish Exomes Reveal Population-Specific Differences in Disease-Related Genetic Variation. *Mol Biol Evol.* 2016 33(5):1205-18. doi: [10.1093/molbev/msw005](https://doi.org/10.1093/molbev/msw005).

Users should note that the CSVS bears no responsibility for the further analysis or interpretation of these data.

## Select dataset

Please, select the dataset you want to access to:

- All
- MGP controls (VCF available at EGA under request <https://www.ebi.ac.uk/ega/dacs/EGAC00001000222>)
- Healthy controls
- MGP + IBS controls + Healthy controls
- All individual except ICD10 group I: Certain infectious and parasitic diseases
- All individual except ICD10 group II: Neoplasms
- All individual except ICD10 group III: Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism
- All individual except ICD10 group IV: Endocrine, nutritional and metabolic diseases
- All individual except ICD10 group V: Mental and behavioural disorders
- All individual except ICD10 group VI: Diseases of the nervous system
- All individual except ICD10 group VII: Diseases of the eye and adnexa
- All individual except ICD10 group VIII: Diseases of the ear and mastoid process
- All individual except ICD10 group IX: Diseases of the circulatory system
- All individual except ICD10 group X: Diseases of the respiratory system
- All individual except ICD10 group XI: Diseases of the digestive system
- All individual except ICD10 group XII: Diseases of the skin and subcutaneous tissue
- All individual except ICD10 group XIII: Diseases of the musculoskeletal system and connective tissue
- All individual except ICD10 group XIV: Diseases of the genitourinary system
- All individual except ICD10 group XV: Pregnancy, childbirth and the puerperium
- All individual except ICD10 group XVI: Certain conditions originating in the perinatal period
- All individual except ICD10 group XVII: Congenital malformations, deformations and chromosomal abnormalities
- All individual except ICD10 group XVIII: Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified
- All individual except ICD10 group XIX: Injury, poisoning and certain other consequences of external causes
- All individual except ICD10 group XX: External causes of morbidity and mortality
- All individual except ICD10 group XXI: Factors influencing health status and contact with health services
- All individual except ICD10 group XXII: Codes for special purposes

# Signatures

For and on behalf of User:

Name of Applicant(s):

  
  
  

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Signature of Applicant(s):

  
  
  

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Date:

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Email to send the download link:

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For and on behalf of User Institution:

Signature of Institutional or Administrative Authority:

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Print name:

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User Institution:

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Date:

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\* It is mandatory to fill in all the fields of the form.

WHEN SUBMITTING THIS DOCUMENT, PLEASE INCLUDE ALL PAGES OF THE AGREEMENT WITH THIS SIGNATURE PAGE